Choosing your Best Urinary Diversion

For Women

Dr. Armine Smith

Stephanie Chisolm:

Okay. Well, we have some time, so let's get to the questions from our participants. I've heard several neo people saying that they've had stones due to the use of staples to form their neobladders. Should a patient not have surgery with a surgeon that still uses staples? Is that a common thing, Dr. Smith, that people use staples to assemble the neobladder that could then, because they don't dissolve, form calcifications and form stones in the bladder?

Dr. Armine Smith:

Yeah, so yes. So staples have no business in a neobladder. Okay, because we use the staples a lot of times to reassemble the GI tract and the urine that comes in contact with the staples can form the stones on the staple line. In the ileal conduit, it's not an issue, because the urine continuously moves. And in the neobladder, in Indiana pouch, it usually stagnant. So it can sit there and kind of form this calcification on the staple line. So what we do usually is remove the staples and we stitch it up. There's some people for Indiana pouch would use the dissolvable staplers, so not the metal staplers. But yes, for anything that's a continent diversion should not have a steel in there. Or sorry, not a steel, but staple in there.

Stephanie Chisolm:

Right. Yeah, Mary, did you have that? Is that what you were saying?

Mary Wink:

I do. I've had x-rays done and they've looked and said, "What has happened?" It looks like I swallowed a box of staples, because I've seen the x-ray and I have lots of staples, but I've not had any problems with forming stones. I've been fortunate not to have gone down that path. But it was quite interesting when I didn't say anything to them when they took the x-ray and then they went, "Oh, what happened?" So it is, it looks like-

Stephanie Chisolm:

Did you swallow staples?

Mary Wink:

Yeah. Did you swallow a box of staples? Because that's what it looks like. I have lots of staples. But fortunately I've not had an issue. Hopefully I won't.

Dr. Armine Smith:

Do you get pulled over at the airport?

Mary Wink:

No, I haven't.

Stephanie Chisolm:

Okay. Well, that's a good thing. So let's go to another question, and I think this is something that you can just speak to Dr. Smith. Can you use supplements to increase magnesium and other things that you're losing because of your diversion, because of that piece of intestine being rerouted? How should patients attack that? How should they talk to their doctors?

Dr. Armine Smith:

Yeah, so I mean, I would discourage people to go and use the supplements unnecessarily unless there is a diagnosis of low magnesium or low potassium. Like I said, the most common metabolic derangement we see is the acidosis in patients who have neobladders. For that sodium bicarbonate or citrate, these are the things that are used. But yes, I think it's okay to use the multivitamins for daily activities, but I would recommend check in with the doctor before overusing these.

Stephanie Chisolm:

Okay, super. This is great. And then let me get to the next question. Is self-catheterizing the answer to urine retention within neobladder?

Dr. Armine Smith:

And that kind of goes to the point that I brought up earlier with the physical therapy. So pelvic floor physical therapy. So usually the first thing we do is catheterize obviously, to let the urine out, because we don't want extra urine accumulating in the neobladder. However, there can be some techniques to help mitigate emptying of the neobladder more completely. So for residual urine, some people will use their abdominal muscles, some people will learn to relax their pelvic floor a little bit better, and the physical therapist can work with them on that. Then there are some people who do the somethings called Credé's maneuver, where you just directly push on your neobladder and help excrete some of the urine. But catheterization is one of the means to get rid of it just because accumulation of the urine can cause problems down the line.

Stephanie Chisolm:

Right. I think a lot of people don't even realize that there is a subspecialty of physical therapy where that therapist focuses on pelvic floor strengthening and just that whole general area. So again, that's a good question to speak with your doctor and to possibly get a referral. Does the history of colon polyps dictate a certain direction if you've had a history? I know you mentioned that earlier in choosing if you've had any problems in your colon previously, but just the polyps, is that something that dictates your choices?

Dr. Armine Smith:

Yeah, I think that can be something that should definitely come up in the conversation with your surgeon. But benign polyps don't necessarily preclude you from using the colon as a segment for a diversion. There are some polyps can be pre-cancerous. There are some people who just form a ton of polyps, which can be a sign of predilection to having colon cancer in the future. So conditions like that will probably make the colon as a pouch less desirable. But yeah, if you're heading down the line, the Indiana pouch, colonoscopy needs to be fairly recent within kind of the recommended guidelines within a couple years or so. And then these are the conditions that one needs to be aware of.

Stephanie Chisolm:

Well, I think the next question, which option holds the biggest active physical limitations? I think you all have addressed that in that most of you haven't said that you have any significant physical limitations. I mean, do you find yourselves challenged?

Anita Cunningham:

I would say that the only limitation that I would be aware of, that I need to be aware of, is with the bag being on the outside and as it fills, then if you were to say, bend down for a long period of time or put extra pressure on that bag, there's only one way for that bag to go, which means it's going to go back into the appliance and it may push liquid out of the appliance and cause a leak. But it's one of those things that I'm aware of and it's manageable. If I feel like my bag is full on the right side, then I learn to pick up something on my left side so that I'm not putting pressure onto that area. That would be the biggest thing. Other than that, I don't really even think about it. I just go about my day. And thankfully, after, like I said, I've been two years out, there's days that I just forget that I have this new normal until I go, "Oh, it's time," and then I have to go and empty the bag and then I'm done.

Dr. Armine Smith:

Yeah. I think Anita it's probably, as you're kind of so rightfully bringing it up, it's very little limitation with the ileal conduit. I think people have the biggest misconception about this type of a diversion. They feel like it's going to preclude them from doing things that they love. A couple of things that I wanted to ask you is how you deal with nighttime. Do you switch your small pouch to a bigger bag? Do you not lay on your side a certain way? Then the second thing is, how do you deal with swimming? Because those are the questions I get asked all the time.

Anita Cunningham:

That's all right. As far as nighttime goes, I plug into a night bag, and so that hangs off the side of the bed and I'm good to go. I sleep all the night through, so that's not an issue. I've heard some weird things. Some people had a tube and they just drained it to their bathroom, and I'm like, doesn't sound right. But yeah, so that's super easy. As swimming goes, I'm not a big swimmer, and so I have yet to be in the pool with it. I have spoken with my Survivor to Survivor person, and she swims and has no trouble. The issue that I think people are concerned about is, will the appliance come off because of the water in the pool? And will there be a leak, because of that? But these appliances are waterproof and they're built that way. And so the adhesion and everything is strong. Usually that won't happen unless you're ready to change the appliance anyways.

Dr. Armine Smith:

And then also there are swimming belts that people use sometimes to cover up the pouch if they want to get in the pool, in a public pool.

Anita Cunningham:

And I use that daily anyways, because I like my pouch laying sideways. And so I use this, oh gosh, the name is escaping me, but it's like a hernia belt.

Stephanie Chisolm:

A Stealth Belt?

Anita Cunningham:

It's a Stealth Belt. Thank you. Thank you. It's a Stealth Belt. I love it. I love my Stealth Belt. It keeps everything close to the body, so you just have no worries whatsoever about this pouch hanging down, filling up, getting heavy, whatever. It just keeps everything streamlined and you're good to go.

Karen Godfrey:

Stephanie, I'd like to say as far as swimming goes with the IP, I am always a little bit nervous about being in a public pool and the health of the pool, so I always have a Suresite type of bandage. It's clear. Dr. Smith might be able to explain a little bit better than I am, but it's something that adheres to your skin for the time that you need to be in the pool and you can take it off. And when I'm doing that, then I have a tiny bit of gauze that I put right over the stoma itself before I put the Suresite on. Then I've got another question about the Indiana pouch and the optimum amount that you think that the pouch should hold, 4-500 CCs. Is that a good stretched pouch?

Dr. Armine Smith:

Yeah, that is usually the amount that we aim for.

Stephanie Chisolm:

Right. Well, I think we're really coming up on time. We've been having a phenomenal discussion. I thank you all.

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